Children's Disability Services Workgroup

Meeting #3
October 29, 2013, 10:00 am – 3:00 pm
Polk County River Place, Room 2
2309 Euclid Avenue
Des Moines, IA 50310

MINUTES

ATTENDANCE

Workgroup Members: Jim Ernst, Chuck Palmer, Marilyn Althoff, Gail Barber, Nicole Beaman, Dana Cheek, Paula Connolly, Deb Dixon, Patty Erb, Jerry Foxhoven, Jason Haglund, Sheila Kobliska, Janice Lane, Marilyn Lantz, Amber Rand, Wendy Rickman, Shanell Wagler, Debra Waldron, Barb Anderson for Susan Walkup

Legislative Representation: Representative Joel Fry

Workgroup Members Absent: Scott Musel, Jason Smith, Representative Lisa Heddens, Senator Nancy Boettger, Senator Liz Mathis

Facilitator: Kevin Martone and Kelly English

DHS/IME Staff: Laura Larkin, Don Gookin, Sally Nadolsky, Carmen Davenport, Theresa Armstrong, Renee Schulte, Jennifer Vermeer

Other Attendees:

Susan Osby	Polk County Health Services
Arnie Honkamp	DHS
Karen Bougher	Polk County Health Services
Kristie Oliver	Coalition for Family & Children's Services
Ann Riley	CDD
Beth Rydberg	DRI
Melissa Fitzgerald	Sequel Youth Services/WACBS
Brice Oakley	AOC, IACMHD, and Orchard Place
Rhonda Rairden	IDPH
Vickie Miene	Center for Child Health, UIHC
Bob Muqueen	Iowa Nurses Association
Danielle Oswald-Thole	Child & Family Policy Center
Aaron Todd	Senate Ds

Representative Dave Heaton	
Susan Whitly	Hillcrest Family Services
Amber DeSmet	LSA
Charlotte Eby	LSI

INTRODUCTIONS AND WELCOME
Jim Ernst welcomed the workgroup member and guests, and asked workgroup members to introduce themselves.

MEETING #2 MINUTES
Jim Ernst asked workgroup members to review the minutes from the second meeting held on October 29, 2013. The meeting minutes were accepted as written.

CHILDREN'S MENTAL HEALTH SYSTEM CORE GOVERNANCE DISCUSSION
Kevin recapped mental health redesign efforts in Iowa with an emphasis on the children's System of Care (SOC) moving forward with success in the area of Integrated Health Homes (IHH). There is still much going on regarding redesign. From a governance perspective the SOC continues to have a focus. We have also discussed the concept of having a Children's Cabinet.

The rationale for the Children's Cabinet makes sense to the workgroup but Kevin wondered about the group's rationale for proposing the Cabinet last year. Kevin also wondered if we need to change the Children's Cabinet concept as it relates to the governance piece going forward.

Workgroup members shared the following ~

- All of these different systems are working toward the same things. We need individuals on the Children's Cabinet that can make decisions moving this process forward. The Children's Cabinet would have high decision making authority.
- The education system often breaks down and then they plan for an out of home placement. We have youth who have assistive technology at school but they are not allowed to take it home to do their work.
- We need to take into consideration rural vs. urban areas and services available to youth. We need the Children's Cabinet to address these matters and for them to make a decision on what is needed.
- The Children's Cabinet needs to have a specific membership and duties. It is important to get a high level membership who can make decisions. No one agreed on the number of individuals on the Children's Cabinet but this can be worked out later.
- We need high level management staff that can make decisions.
- Many decisions regarding youth are not made by state governmental agencies. Some decisions may be made by primary insurance providers.
- We need many voices on the Children's Cabinet.
- I believe this would end up being too large and ineffective. How do we include the grassroots parents' voice along with the high level decision makers? Many

youth are isolated due to geographic and we are not doing much to help them. We do not have access to different innovative ideas like micro boards.
- This concept needs to be integrated across silos.
- A policy driver or key leaders are needed to make decisions. We need to have others to provide feedback on what is working and what is not working.
- The legislature is nervous about the number of advisory councils. It is a solution looking for a problem. The legislators need to question why the groups are developed in the first place.
- DHS has looked at things from a Child Welfare perspective in relationship to the councils/advisory groups. We have to figure out what will occur here before we can end current council/advisory groups. DHS has to satisfy federal guidelines in relationship to having diverse groups ~ public, private, youth, and family.

Chuck reported that we have spent a lot of time on SOC and IHH and making it part of the delivery system at the local level. We need a state level group that can provide oversight and set the standard/model. Kevin shared the Children's Cabinet could be the central point of coordination for the children's system of care. Kevin talked about having 2 councils ~ a State Interagency Council and an Advisory Council for children. The State Interagency Council would be comprised of state agency leadership. The Advisory Council would bring ideas/concerns from the provider network to the State Interagency Council.

Joel Fry reported that the legislature is in the mode of reducing bureaucracy and reducing workgroups/councils. Joel asked specifics related to membership, responsibilities, and decision making authority. It is important to focus on outcomes. Mental health services for adults have been discussed for 4 years in an effort to get it launched well. Once this is accomplished, they will work towards moving children's services forward.

Kevin reported that if Iowa wants to move the SOC forward it will need a single focus point to carry the torch. The state agencies oversee most of the groups in existence now and are probably in the best position to carry out what the Children's Cabinet want to do. It is the right decision to reduce the groups/councils and make decisions now on which ones to keep.

The State Interagency Council will include the following membership ~
- DHS ~ child welfare, mental health, IME
- Education
- Public Health
- Court/Judicial
- Vocational Rehabilitation
- Management (Early Childhood)
- Division of Insurance
- Human Rights

The Advisory Council will include the following membership ~ (10-15 members)
- Family members

- AEA
- School Districts
- Providers ~ primary care, juvenile justice, specialty care, mental health, child welfare, disability services, addiction
- Others designated by the group

Workgroup members discussed details related to both councils in terms of membership, responsibilities, decision making authority, length of terms, etc. Kevin cautioned the workgroup members about being too prescriptive. It is important to focus on the tasks at hand ~ standardized assessment tool, youth with high needs, transition age youth issues, overseeing/advising on core services that the workgroup discussed during the last meeting. One workgroup member expressed concern that nothing was being done to address issues for DD youth.

Kevin reminded the workgroup that the charge is not narrowly focused and will address all youth. Other workgroup members shared that the final report needs to cite specifics in this area.

PUBLIC COMMENT

Comment: Embrace the SOC in schools. The principle lacking are family voice and family choice. Families who are a part of the service system have insight that others do not have.

Comment: Our care system is broken and we are trying to help people in need. I have listened to many sessions, and note that your thoughts and concepts are wonderful. It is difficult to implement all the wonderful ideas. I am afraid if we do not listen to grassroots efforts, like families and providers working the front lines, there is a danger of not hearing their voice and meeting their needs. Their voice is important and the Legislature needs to hear their voice. NAMI is good at promoting grassroots efforts. Remember to use technology to get information across the state and listen to feedback. If we want to use our dollars wisely, you have to listen to the voices at the local level.

Comment: It is important to focus on the governance issue. These are my personal views. I think this discussion is a political science issue. It is important to give an entity policy implementation authority and rule making authority. It is important to focus on policy advising. The Governor can create such an entity to fulfill this purpose. Be mindful to avoid creating another group which in turn creates another budget item and creates new kinds of reporting measures. Advisory councils already exist and do not have the authority to make policy. We need an inclusive voice from citizens, and could use citizens from other groups. This is a political science exercise within the Executive Branch. Keep it simple and keep it effective.

Comment: I have a number of comments ~

1. I expressed concerns about the Cabinet last year. I was concerned it would create an extension of this workgroup. How is the advisory group different from what this group is charged to do? I fear this will not accomplish anything.

2. The Child Center for Excellence fosters and supports innovative strategies at the local level. We take decisions that are made and funding to make it happen at the local level.
3. We need to have families at the table.
4. I agree that IME needs to be at the table. IME is a large payer and is instrumental in implementing services that are tied to this charge.
5. I would urge you to talk about ALL children/youth. it is important to take a prevention perspective and use of early intervention to prevent larger problems down the road.

STANARDIZED ASSESSMENT RECOMMENDATION

Before discussing Standardized Assessment, Kevin reported to the workgroup that the DRAFT Report will be sent to them by 11/08/13. This will allow time for workgroup members to read/study the draft report. The report will be edited by 11/14/13 to ensure that it is due by the deadline of 11/15/13.

Kevin also approached the idea of having a telephonic meeting on 11/12/13. The sole agenda item on 11/12/13 is to review the draft report. This could be done in a 1-2 hour telephonic meeting depending on the discussion. It will be an open meeting, and guests can join the call. The discussion will be limited to the workgroup members.

An addition to today's agenda included a handout that was enhanced with DD services by workgroup members. Jim Ernst will lead the discussion later in the meeting.

Kevin asked about comments regarding the Standardized Assessment Tool Recommendation handout which is in DRAFT form. Kevin was specific about wanting feedback on concepts and how this fulfills the workgroup's charge. Kevin noted that a standardized assessment is designed to streamline data and to drive/start the clinical process. The standardized assessment is viewed through a mental health lens. Other ideas to consider would be to approach the State Interagency Council to pull together clinicians to make a recommendation or the Advisory Council could ask clinicians to participate and help in the decision making process on identifying a standardized assessment.

Workgroup members offered the following comments ~

- I am a supporter of reporting system performance. We need to focus on IT and data collection. We want greater capability to use data to measure performance. There are lots of assessments to use but this does not address co-occurring disorders. It is important to proceed with caution in using a standardized assessment and then is limited in getting the data from providers.
- This group cannot work in isolation from other groups. We need to address data and it would behoove us to mirror other processes like SIM mental health group and Iowa's Health and Wellness. When talking about youth, the assessment is one piece of the system. As long as providers use valid tools then the data should be there. We need to look at things broadly.

- Let the workgroup decide what is meaningful to measure ~ youth remaining in the home, attending school, getting medical needs met, etc. High level outcomes are different than low level outcomes in direct care.
- From a family perspective, they generally go through 3 assessments. This will create an additional layer of bureaucracy and creates burden for the family. We need to flush out what we will measure and when we will measure it. This will be a functional assessment and providers can use other tools for treatment purposes. We can use the data to inform the system and legislators can use the data to determine funding.
- State agencies are not the only ones who work in silos. Private agencies work in silos too. Private agencies have a lot of confidence in what they do. Deciding on a tool that is less perfect from an agency perspective but is one that is perfect from a systems perspective is difficult. It is a place to start. It will be important to identify system level outcomes and outcomes for the domains.
- This will give us a place to start from, and then develop treatment services and identify gaps in services to improve the system.
- We need to look at domains and assessments for each domain. What will we measure? It is a disservice to youth if we ramrod the assessment through.
- The SIS is used for adults.
- We will need a functional assessment to ensure funding in the future.
- With only a mental health lens, we are in a silo. What outcomes do we want to identify and then funnel down to the provider level?

Renee reported that the whole concept of defining this differently is not helpful to legislators. This does not get the funding that is needed. On the adult side, working on standardized outcomes was difficult to achieve. We must avoid lack of consistency in outcomes/assessment. Renee asked if there are educational assessments that are used. Educational assessments focus on education outcomes, but there are things we can learn from educational assessments; we need to look at these per a workgroup member. A workgroup member identified a number of assessments that measure the same things and were developed for ages 0-5.

Representative Fry reported that it took a specific workgroup to identify outcomes for adult core services.

Kevin shared that a standardized assessment does not define the system. It is a place to start, and it could be something for workgroup members to work from and identify what is needed. It will take months to identify outcomes and for the group to agree on the outcomes. It will take time to come to a consensus on outcomes. The SOC has to be able to measure outcomes across domains. This is beyond the scope of what this workgroup can decide on now. It is a step that has to be taken.

In summary, Kevin shared that the standardized assessment tool must be valid and reliable. Identifying a standardized assessment tool may be a task for the State Interagency Council to ask the Advisory Council to identify. This workgroup is not ready to identify a specific standardized assessment tool. We need to have a checks and balance system to present to Legislators. We do not need to be prescriptive at this

point in time. We need to include clinicians and policy staff in identifying a standardized assessment tool to use statewide.

CHILDREN'S MENTAL HEALTH ELIGIBILITY DISCUSSION

Kevin asked the workgroup to look at how youth are eligible now. He did not suggest that eligibility change. Youth become eligible for Medicaid based on certain criteria. Some youth are not covered by Medicaid services now but it is small compared to the youth who are eligible for Medicaid.

Workgroup members shared the following ~

- Youth involved in SOC/IHH are eligible for Medicaid. Other youth will be captured through other state services.
- There are youth that are funded through block grants because they are not Medicaid eligible. How does this impact youth moving forward?
- Youth in care are automatically eligible for Medicaid and when they go into residential services, but other youth are not. We need to wrap services around youth without Medicaid coverage when they leave residential services. CINA youth generally maintain their eligibility based on their family income, but JCO youth generally do not.
- Autism services are limited at this time. Will this group make a statement regarding expansion of services for the DD population?

Chuck shared that it is difficult to talk about eligibility now with the ACA and ACOs. Let's focus on the change we are introducing right now so we do not miss the boat. We cannot just expand right now. We have to maintain focus on the charge.

CHILDREN'S MENTAL HEALTH SYSTEM COUNCILS DISCUSSION

Kevin asked the workgroup if they had any thoughts about other councils that exist and what the State Interagency Council will look like. Will this reduce the current number of councils in existence?

Joel Fry wondered if the workgroup could make specific recommendations on the State Interagency Council. This agency would be a starting point for children's services.

Chuck reported that we need to consolidate the current group and this needs to be thought through. Kevin asked if there were committees or groups that have been consolidated in recent years.

A workgroup member shared that about 6 years ago, we were asked to consolidate groups/committees. The Legislature did nothing with the report as too many people were in disagreement and the number of groups remained the same. We could focus on identifying the purpose of the groups/committees and focus on overlaps.

Renee reported that Legislators and the Governor will add sunset clauses to new groups. If future groups need to continue, the group will have to justify the need to continue.

Jim began the discussion on the handout on Youth Proposed Core Service Domains and Core Services that was edited by workgroup members representing the DD population. A workgroup member reported how this was edited to support services needed by the DD population. The added language to broaden the domains and core services was noted in red. Part of the process was to create a system that did not exist before. Children were not part of the county based system in the past. This is a futuristic view, but it should be our goal.

Renee expressed that the children's core services should mirror adult services.

Kevin shared that when we looked at the domains and core services it was noted that Magellan does cover a number of the services on the list, and we wanted to make sure the system has the ability to pay/provide most of the services.

Workgroup members shared the following ~

- We looked at adult services but those services did not work for youth. If we are talking about ALL youth, then these services are designed for youth. CMS is a major payer and wants to be innovative with services. CMS wants us to think outside the box. We could par this down for services within the next year, but I want to think beyond one year.
- I believe we may need to temper the list with reality, and do some compromising/deletion of what are the core basic minimums.
- Develop a 1-2 year plan, and a 2-5 year plan.
- Part of the process was to create a system that did not exist before. Children were not part of the county based system in the past. This is a futuristic view, but it should be our goal.

Chuck reported this document is viewed through a mental health lens and a DD lens. The process will be for the legislature to move the services into legislation. Chuck talked further about the planning process occurring within the regions and how to serve individuals without Medicaid coverage. We have a long ways to go on the children's side to have adequate funding to address a signal source of governance. We can address this in the final report, and note that all of this will be vetted over time. Regions will not be expected to take on children's services right now. Some counties may not adopt this at all.

Joel Fry reported that this list requires that legislators understand children's services and what the legislators need to cover over the next 2 years. We need to balance this list with realism and cite future goals.

Renee reported that adult core services were designed to be available no matter where you lived in Iowa. This list of children's core services is futuristic. The children's workgroup did take a different direction. It is necessary to identify service minimums for children in each county. Many counties will not be able to do all that is listed on the children's core service list.

Kevin reported that the final report will list the children's core services and aspirational core services to consider in the future. Kevin also reported on the format for the final report. The final report will be 15-20 pages in length.

PUBLIC COMMENT

Comment: Learning more about the various assessment tools available has helped us to educate others and justify continued funding. This group did not address the non-Medicaid group of youth. A single tool is not enough. We need to measure function vs. symptoms. Providers did a functional assessment tool and used it with clients to measure functioning at home and school. It was modified as part of the grants from DHS and modified to use with youth. We found it helpful more so than any other standardized assessment. We do not have time to do all the outcome measures with clients. The best tool is the One Goal Attainment Scale. The client sets the goal, and it is simple to use for both the provider and the client.

Comment: During the last meeting I talked about transition age youth. Youth that are in the foster care system/PMIC have Medicaid automatically. Youth outside the foster care system do not have ongoing Medicaid. This needs to be addressed during the next Legislative session.

Comment: Thanks for including Early Intervention and Early Prevention in the core services. I would recommend adding screening for toxic stress and family stressors. Medicaid does pay for screenings.

Comment: We could invest in and get through all youth through their Primary Care Physician and screen for toxic stress. This could lead to developmental delays and mental health issues in the future if this is not addressed.

WRAP UP AND ADJOURN

The next meeting will be held telephonically. Workgroup members can submit comments to Renee Schulte if they are not able to attend the telephonic meeting. A conference call number will be provided to workgroup members and guests for the telephonic meeting.

****Next meeting: November 12, 2013 @ 10:00 am CST**